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Social support and illness perceptions among users of online communities

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Background

- ❖ Internet-based support groups have emerged as a resource that may be helpful to people suffering from chronic illness as an aid to cope more effectively with the disease. The number of newsgroups, forums or bulletin boards created for Spanish-speaking patients is increasing. In these groups, participants seek information and/or share concerns about their illness conditions.
- ❖ Most of the previous research have focused on analysing the content of the messages posted and have studied virtual groups for one specific illness.
- ❖ Recent studies on face-to-face support groups have proposed the role of illness perception (Leventhal et al., 1997) and beliefs about support groups (Ajzen, 2002) in predicting the participation in these groups (Grande, Myers & Sutton, 2006).

OBJECTIVES

- Describe the **pattern of use** of internet-based groups among people suffering from different types of illness conditions.
- Study the differences in **informational usefulness** and **emotional support** among several sources of support into each illness group and across disease conditions.
- Compare the differences in **illness perception** across online communities users suffering from different disease conditions.
- Explore the **relationship** of support from internet groups and illness perception to **level of participation** in electronic groups.

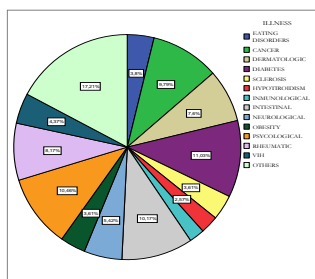
METHOD

Data were gathered using an **on-line survey** made available to different Spanish-speaking bulletin boards. Survey contained questions about:

- ❖ **Socio-demographic and illness related variables** (age, sex, education, type of illness, duration)
- ❖ **Internet groups pattern of use** (frequency, level of participation)
- ❖ **Informational and Emotional Support** from several sources (health professionals, family, friends, patients associations, electronic groups)
- ❖ **Positive views about internet groups** (intention to recommend these groups, internet groups avoid isolation feelings)
- ❖ **Illness Perception** (Spanish version of the "Brief Illness Perception Questionnaire", BIPQ, -Broadbent et al., 2006-)

Survey was completed by **1052** patients suffering from several illness conditions (cancer, diabetes, sclerosis, rheumatic diseases, dermatological problems, intestinal conditions, eating disorders, other psychological problems, etc.).

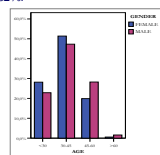
RESULTS



Percentage of participants by illness condition

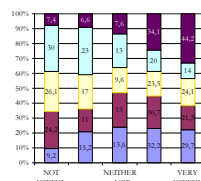
❖ A large number of participants (**69.6%**) were **females**, the mean age was 37,42 years and the mean duration of their illness was 5,81 years (1-7 years).

❖ **50%** of the respondents had a university degree and the percentage of people in work was **62%**.



Respondents by gender and age

HOW USEFUL ARE.... FOR OBTAINING INFORMATION ABOUT YOUR ILLNESS?

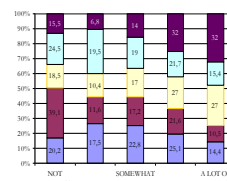


■ HEALTH PROFESSIONALS ■ ASSOCIATIONS OF FAMILY/FRIENDS ■ ONLINE GROUPS

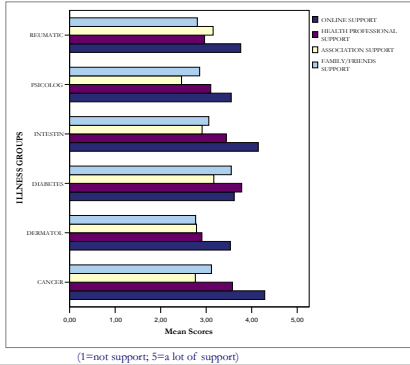
❖ The majority of respondents (**78%**) perceived online groups as useful or very useful for obtaining information about their illness or their treatment.

❖ Health Professionals were viewed as a useful source of informational support (**62%**). However, when asked to what extent they felt emotionally supported by health professionals, **39%** of participants answered "supported or very supported".

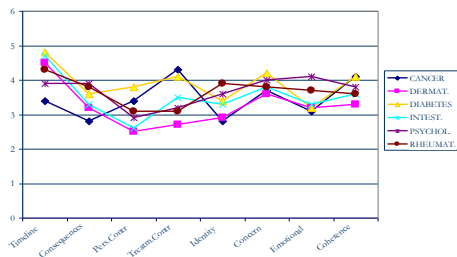
DO YOU FEEL SUPPORTED BY...?



Total Support (informational and emotional) mean scores from online groups, health professionals, patients associations and family/friends



Illness perception means across disease conditions



Diabetes and Cancer: ↑ personal and treatment control ↑ coherence

Cancer: ↓ timeline ↓ consequences ↓ identity

Rheumatic: ↑ consequences ↑ identity

Dermatologist: ↓ personal and treatment control ↓ coherence

Illness perception by level of internet forum participation

ILLNESS PERCEPTION	Cancer			Diabetes		
	High (n=66)	Low (n=35)	p	High (n=33)	Low (n=78)	p
Personal Control	3,70	3,00	<0,010	3,87	3,72	ns
Treatment Control	4,40	4,22	ns	4,36	3,97	ns
Coherence	4,33	3,91	<0,010	4,42	4,00	<0,05
Emotional Response	3,19	3,11	ns	2,81	3,44	<0,05
Consequences	2,74	3,02	ns	3,39	3,76	ns
Concern	3,68	3,71	ns	4,30	4,21	ns
Identity	2,78	2,74	ns	3,66	3,27	ns
Timeline	3,40	3,42	ns	4,57	4,91	0,05

Illness perception by level of internet forum participation

ILLNESS PERCEPTION	Rheumatic Disease			Psychological Problems		
	High (n=30)	Low (n=44)	p	High (n=37)	Low (n=63)	p
Personal Control	3,17	3,09	ns	3,02	2,92	ns
Treatment Control	3,10	3,25	ns	3,18	3,14	ns
Coherence	3,73	3,59	ns	3,67	3,79	ns
Emotional Response	3,80	3,56	ns	3,94	4,18	ns
Consequences	4,26	3,54	<0,01	3,75	3,98	ns
Concern	3,80	3,86	ns	4,10	3,96	ns
Identity	4,33	3,75	<0,05	3,48	6,64	ns
Timeline	4,53	4,02	ns	3,81	4,06	ns

Support and views about support groups by level of forum participation

	Cancer			Diabetes		
	High (n=37)	Low (n=35)	p	High (n=30)	Low (n=44)	p
Support from Internet Group	4,55	3,85	<0,010	4,03	3,56	<0,05
Positive views about Internet Groups	4,71	4,47	0,05	4,63	4,04	<0,001
	Psychological Problems			Rheumatic Disease		
	High (n=37)	Low (n=63)	p	High (n=30)	Low (n=44)	p
Support from Internet Group	4,17	3,17	<0,001	4,27	3,51	0,001
Positive views about Internet Groups	4,48	3,92	<0,010	4,40	4,14	ns

Discussion

- ◆ In general terms, comparing with other sources, online support groups are viewed as a powerful source of informational and emotional support.
- ◆ Results show that, although for some groups of patients, such as diabetics or people with cancer, who feel supported by health professionals and family/friends, for other illness groups, such as people with dermatological or rheumatic problems, health professionals are not perceived as a supportive source. Perhaps, this fact might be pushing them to turn to internet to find help for managing their illness.
- ◆ More research is needed to explore the relationships between the use and participation in online groups and different health outcomes, such as quality of life or psychological well-being.